## INDIANA PROTECTION AND ADVOCACY SERVICES











TO PROTECT AND PROMOTE THE RIGHTS OF INDIVIDUALS WITH DISABILITIES,
THROUGH EMPOWERMENT AND ADVOCACY



THE PROTECTION AND ADVOCACY SYSTEM FOR INDIANA

MEMBER, NATIONAL DISABILITY RIGHTS NETWORK

## We Believe...

all individuals must be treated with dignity and respect

all individuals must have equal access

all individuals have the right to self-determination and self-expression

all individuals with disabilities have the right to services that address their unique needs, and are provided in the least restrictive environment

that our first responsibility is to our client

that together we make a difference

## Independence through IPAS

- EDUCATION & EMPLOYMENT
- COMMUNICATION
- TRANSPORTATION & MOBILITY
- ACCESSIBILITY
- ADVOCACY

Today, there are more than 54 million Americans living with disabilities.

For these people and their families, every day presents a new challenge. Communicating with others, getting from place to place, working and even recreating can be made difficult, or sometimes impossible.

The Indiana Protection and Advocacy Services Commission (IPAS) helps Hoosiers maintain—or regain—their independence through addressing these and other barriers. IPAS defends the rights of people with disabilities and extends them equal opportunity and empowerment.

# IPAS Defends the Rights of Citizens With Different Abilities and Extends Equal Opportunity and Empowerment to People With Disabilities.

## IT'S OUR RESPONSIBILITY

History has taught us that when any group of people is treated unjustly or denied rights, the fabric of our community is weakened. We all benefit when we affirm and defend the right of every citizen to participate in society, make contributions and fulfill their dreams.

### PEOPLE WITH DISABILITIES HAVE RIGHTS UNDER THE LAW

A disability is a physical or mental impairment that substantially limits one or more major life activities. The United States Congress recognizes disabilities as a natural part of the human experience, and to help ensure that no one is excluded from mainstream society, Congress has enacted laws providing support services and programs for people with disabilities.

People with cognitive, mental, sensory and physical disabilities are protected against discrimination, abuse and neglect. Like all other Americans, they have the right to live their lives as fully and independently as possible, and with the freedom to make their own decisions to the extent of their abilities.

### PROTECTED BY LAW. ASSISTED BY IPAS.

To defend the human, legal and civil rights of people with disabilities, Congress established protection and advocacy (P&A) systems in each state. Indiana Protection and Advocacy Services Commission (IPAS) provides these services in Indiana.

## TOO OFTEN, INDIVIDUALS WITH DISABILITIES ARE:

- abused or neglected by caregivers;
- denied appropriate medical, habilitation, or psychiatric treatment;
- denied free and appropriate public educational services;
- denied physical access to public places and governmental services;
- discriminated against when trying to obtain employment or housing;
- denied the ability to make their own decisions and be a fully participating member of their community;
- denied the assistive technology services or devices they need to be more independent;
- experiencing private information released to others without their consent; and
- denied the right to make their own choices as they prepare for employment through Vocational Rehabilitation or Ticket To Work training programs.

### **IPAS CAN HELP BY:**

- helping you understand your rights;
- helping you learn self-advocacy skills;
- advising you on what steps you can take to secure your rights, such as appealing denials and filing complaints with appropriate governmental agencies; and
- representing you with an IPAS Advocacy Specialist or IPAS Attorney to correct rights violations.

EVERY YEAR IPAS REPRESENTS HUNDREDS OF HOOSIERS WITH DISABILITIES IN SECURING THEIR RIGHTS TO FULL COMMUNITY PARTICIPATION. IPAS HELPS THOUSANDS MORE THROUGH INFORMATION AND REFERRAL SERVICES.



## **Education & Employment: Independence through IPAS**

Jean is not the typical Hoosier college student. The 52-year-old self-proclaimed "aging hippie on campus" is pursuing a bachelor's degree in humanities at Indiana University East, and is loving every minute of it.

But a few short years ago, Jean's life was very different. Jean suffers from recurring major depressive disorder, social phobia and traumatic stress syndrome, and has received medicinal treatment and psychotherapy since 1989.

"I was married for 26 years—and he was not a nice person," Jean shared. "When we did finally divorce, I thought I was going to lose everything—including my 16-year-old daughter—and be penniless. I knew I had no chance. And the day of the final hearing, I ended up in a psych ward at a local hospital."

After this ordeal, Jean began the process of counseling, which for her also included vocational rehabilitation. It was this experience that led her to IPAS two years ago.

Jean had been receiving vocational rehabilitation to help her start her own cleaning and pet care business, but she really wanted to go back to college. Unfortunately, the state vocational rehabilitation program did not agree that college was necessary for Jean to operate a successful business.

"I felt I was getting stonewalled and not being heard-I was getting nowhere," Jean said.

Then, Jean was introduced to an advocate from IPAS.

"She was the first person who gave credence to my concerns," Jean recalled. "I remember thinking, 'Wow, someone heard me and really listened.' She drove up

here from Indy; we sat down and talked, opened up the line of communications, and set the groundwork for my new education goals. She negotiated the whole thing."

Because of the advocate's intervention though IPAS, Jean is now back in school full time and is earning straight A's. And she feels right at home in the Fine Arts School, where she takes classes in graphic design and ceramics.

"IPAS helped put me in an environment where I didn't feel like a square peg anymore," Jean shared. "I met with tremendous success academically. Most importantly, I feel nurtured—and even though college is a sheltered environment, I now see a future for myself not only on a day-to-day basis, but down the road."

Jean now aspires to get her master's degree and is seeing hopes and dreams she was denied for 26 years.

"Without the intervention, I might have balked at the change in my vocational rehabilitation, thinking they were playing a game," she said. "I didn't trust anyone. But IPAS was an incredible surprise to me. Somebody listened."

Jean says she is a testament to the fact that "even aging hippies can go back to school and succeed."

"When I share what I have done with other people, it gets them thinking—you are never too old to keep trying," Jean said. "Through the help I received from IPAS, rather than saying I'm too old, I have been able to dream, and live my dreams. It is never too late."



## Communication: Independence through IPAS

When pediatric rehab nurse Cheryl adopted her daughter, Rameisha, at the age of four, she was already a million dollar baby.

A slew of health problems had left Rameisha on a ventilator and with a feeding tube.

"It was actually a blessing that we adopted her out of Pennsylvania, because she was new to the Indiana Medicaid system," Cheryl explained.

However, Medicaid expenses for Rameisha added up quickly. Recently, the family's claim to get Rameisha a communication device was denied.

"Since she doesn't speak, we felt it was critical to get Rameisha a Springboard to help her communicate," Cheryl said.

The family had prior authorization from Medicaid to purchase the small, handheld touch screen device. But, the amount Medicaid was going to pay would have created a loss for the company that makes the device—and they didn't want to take that loss. The family's claim was denied.

In response, one of Rameisha's speech pathologists directed Cheryl to IPAS. "IPAS helped negotiate, and worked with Medicaid to agree on an acceptable amount," Cheryl said. "Our case was actually successfully resolved in six to eight weeks."

Cheryl says that their experience with IPAS was a tremendously positive one.

"There was never a thought that we couldn't get this accomplished, it was just a matter of when," Cheryl shared.

Today, Rameisha is 8 years old and doing well. She uses her Springboard every day to increase her ability to communicate at school and with her family. In fact, a recent update to its software has further enhanced this augmentative communication device.

Cheryl feels it is important that people are aware that IPAS is out there.

"IPAS is all for individuals who have disabilities and helping them get what they need to be independent and have good quality of life," she said. "There are so many people who need so much help, but don't know how to do it. In our case, the fact that I was willing to fight helped, but it's nice to know there is someone ready and able to help us in that fight."

NOTE: Rameisha's experience with IPAS led to positive life changes not only for her, but for other Hoosiers needing this communication device. The 8-year-old's case allowed IPAS to trail blaze an entire systems change to benefit many other individuals with disabilities. On behalf of Rameisha. IPAS contacted Prentke-Romich, the vendor who manufactures the speech device. In response, the company contacted Indiana Medicaid, which decided to set a higher Medicaid reimbursement rate for the device. Prentke-Romich then went back through their records and made contact with all individuals who had previously received denials for the device due to the low Medicaid reimbursement rate, offering to provide those same individuals with the device.



## Transportation: Independence through IPAS

In 1991, Daniel was an active guy who enjoyed playing rugby with the Indianapolis Rugby Club and had plans to attend Ball State University. That year, a sports related spinal cord injury would change his life—but not his aspirations.

Daniel completed an undergraduate degree in criminal justice, and earned his master's degree in counseling psychology. He then set out to help other people whose lives had been impacted by a disability.

This road led Daniel to employment with the Indiana Protection and Advocacy Services Commission (IPAS). As an intake advocate, Daniel helps determine whether requests for help are in line with IPAS's priorities, putting them on the road to resolution or providing technical assistance or referral.

Naturally, Daniel was aware of IPAS's programs when he found himself in need of the organization's support, too. Daniel has been an IPAS client on two cases, both related to a modified vehicle that allows him to drive from his wheelchair—and more importantly, to maintain his independence.

Daniel's vehicle has been modified in many ways—the floor has been lowered, a lift has been installed, and it has adaptive devices that allow him to steer the vehicle and control all of the other vehicle functions.

When vocational rehabilitation denied payment for a repair to one of the modifications, the prohibitive cost of fixing his unique vehicle could have been a big setback for Daniel. But with the help of IPAS, his appeal was a success.

"For me, it boils down to choice," Daniel said. "IPAS works to ensure our client's choices regarding the type of services they receive that help improve quality of life. For example, I choose to have a vehicle I can drive myself. Sometimes people need an advocate to make sure they know all of their options. Then they can make their own decisions without the concern of having their rights denied."



## **Mobility: Independence through IPAS**

Six-year-old Levi is a huge NASCAR fan. In fact, this card-carrying Tony Stewart Fan Club member will meet his idol at a picnic this summer.

And he will do it in his orange electric wheelchair.

The motorized wheelchair allows Levi to get himself out on the playground—or anywhere he wants to go—all by himself. But four years ago, this independence was threatened when it appeared that the tiny 2-year-old would be limited to a manual wheelchair he was too small and weak to operate.

Even though Levi has polymicrogeria, which led to cerebral palsy, his family's claim was denied by Medicaid four times, explained Pam, Levi's mother. That was when they sought help from IPAS.

"Medicaid said Levi should be able to use a manual wheelchair, but because he is weak on his right side, we would have had to push him around at all times," Pam explained. "It would have deterred his independence."

Fighting for Levi's independent mobility had consumed his family's life for almost a year. They had gathered nine letters of support from everyone from therapists, physicians and a wheelchair specialist at Riley Hospital for Children. But it wasn't until an IPAS attorney came into the picture that things began to move in the right direction.

"He was wonderful—he really went above and beyond for us, including hand-delivering paperwork to us in Danville and making a special trip to Levi's school to meet his therapists," Pam said. "He was determined that Levi was going to get that wheelchair."

The hard work of the attorney-and IPAS-was a success. The electric wheelchair has not only allowed Levi to be more mobile and independent, but more comfortable, too.

"It helps him maintain better posture, and when he drives himself out onto the playground, he feels more normal, like other kids," Pam explained. "Plus, the wheelchair will go seven miles an hour. That's important to a NASCAR fan like Levi."



## Accessibility: Independence through IPAS

Two years ago, 13-year-old Anthony was looking forward to his family's trip to the Indiana State Fair. Much like any other child, he was excited to sample the sinful fair food, play games on the midway, and most importantly, see his cousin's blue ribbon winning entry displayed in the 4-H building.

Unfortunately, Anthony's much anticipated trip to the fair would end in tears. Anthony has cerebral palsy, and his family quickly discovered that the state fairgrounds was not fully accessible to him and his power wheelchair.

"There was inadequate accessible parking," shared his mother, Karen. "There were no accessible bathrooms in the 4-H building, and his cousin's projects were displayed on the third floor, where Anthony couldn't go. He was devastated, he never got to see the display."

Karen had sought help from IPAS once before to help reinstate Anthony's Medicaid after a move. Now, she turned to the organization again to advocate for Anthony at the state fairgrounds.

"It's not fair when you go out as a family to enjoy yourself, and there is a barrier," Karen said. "Everyone wants to enjoy leisure and recreation, and we all want to be active in the community. Even with passing of the Americans with Disabilities Act in 1990, there are still architectural barriers—like the ones we discovered

in the 4-H building—that keep people from living a full life. Anthony shouldn't have to deal with that."

IPAS agreed. The organization began to help Anthony and his family with their case, and was successful in ensuring changes to the state landmark were in compliance with the Americans With Disabilities Act. Today, the Indiana State Fairgrounds 4-H building is now accessible to all Hoosiers. Other areas of the fairgrounds, including parking, have been improved, too.

Karen is pleased that her family's—and IPAS's—advocacy efforts were able to help others, too. The Indiana State Fairground officials have and are continuing to make the grounds accessible to all.

"People who have family members with disabilities are dealing with barriers all the time," she shared. "This is one place that we won't have to do that anymore."

Although Anthony hasn't had a chance to go back to the fair, he is extremely active. He plays power soccer in his wheelchair on an Indy Parks team, loves video games and enjoys bowling and swimming. Next year, he will begin his sophomore year with 51 percent of his time spent in regular classrooms.

And through the help of IPAS, the number of places he has access to is growing every day.



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